

...offering  
information and  
*inspiration* to  
individuals with  
disabilities and  
their families as  
they direct their  
own supports and  
services



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## Real Life Choices is Launched

Nearly 100 Families Begin the Journey

Families have long been the backbone of the service system for people with developmental disabilities. Nearly two thirds of the more than 30,000 people served each year by the Division of Developmental Disabilities are living at home with their family. Until now, these individuals and their families saw little support. In fact, analysis of DDD's budget shows that less than 7% of DDD's \$1.06 billion dollar budget was allocated to these individuals.

Recognizing the need to establish more equity and fairness in the allocation of DDD's resources, and the national service trends toward more person-centered, self-directed services, the Division launched Real Life Choices last year.

According to DDD, **Real Life Choices is not a 'program' or 'pilot.' It represents a whole new way of doing business - a system change.**

"We hope this new model will give families and individuals the flexibility to make choices and decisions about what they want and need," said Kathy Palsho, Director of New Programs at DDD. "This will bring help and support to families earlier in the process and focus on supporting individuals where and how they live."

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Real Life Choices is the blueprint for services announced in the fall of 2002 by the Department of Human Services. The Division has four major goals in implementing the program: equity in the distribution of service and resources; family and individual decision-making; allocation of comparable resources for comparable levels of need; and development of individual budgets based on those needs.

Implementation of the plan began this fall with 200 families on the Division's Category One waiting list for residential services in 5 counties (Atlantic, Camden, Cape May, Somerset and Union). Depending on the level of need assigned, they will be allowed to spend from \$14,000 to \$63,000 a year to purchase whatever services their loved one needs to live more comfortably at home. Another 100 families from Bergen, Mercer, Middlesex and Passaic counties will enter the program before June.

Real Life Choices will eventually go statewide. When it does, many believe it will reduce the 7,000 person waiting list for traditional residential services, such as group homes and supervised apartments.

In the past, the only way to get services was to get placed on the Division's waiting list. State officials estimate that roughly 60 percent of the families who sign on to the



## *Creating Support in Places of Worship*

**J**essica grew up in a family that had a strong church focus. They always attended Sunday church services. Jessica, who was 10-years-old at the time, developed the habit of calling out, “Help! Police! Get me out of here!” throughout the service, most often during the sermon. Her mother, being frustrated and embarrassed, would grab Jessica’s hand, take her into the hallway, and not so gently remind her that church attendees are supposed to be quiet in. In her more frustrated times, Jessica’s mother remembers telling her, “None of us want to be here, but you can’t yell it out at the top of your lungs in the middle of church.” Jessica, who had significant cognitive impairments, was amused by her mother’s reactions to her outbursts but showed little willingness to alter her behavior. Church members, knowing Jessica and her penchant for independent action, tolerated her outbursts most of the time. Jessica’s yelling, however, truly did disrupt the service.

Jessica’s mother did not want to change the family’s church attendance practices and was determined not to exclude Jessica from the church service. Seeking solutions to the problem, she talked with Jessica’s Sunday school teacher, the Bishop and other church people actively involved in Jessica’s life, and members of Jessica’s community team. They all brainstormed to try to understand what was motivating Jessica and what strategies could be used to stop Jessica from shouting out in church.

Together, Jessica’s family and the people with whom her mother discussed the problem hypothesized that Jessica’s behavior was motivated by boredom and her lack of understanding church service practices and the service content. The “team” investigated ways to address these issues. As for Jessica’s boredom the team thought it would help Jessica if she could sit next to a friend and had manipulatives she could hold in her hands to entertain herself during those moments when she found it hard to pay attention to church activities.

The more interesting “team” activities, however, focused on making the church service more understandable and

accessible to Jessica. The Bishop gave Jessica a series of tapes of common church hymns so that Jessica could listen to them at home and other places and learn the words so she could sing along. Jessica’s Sunday School teacher gave Jessica a set of scriptures in cartoon form so that she could get some meaning from them. Church members bought her video tapes of church stories and worked with Jessica’s mom to give advance notice of what scriptures would be discussed and what hymns would be sung at upcoming services.

... the experience with Jessica  
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The church service structure was adjusted to permit Jessica to take a more active, public part. She sat with the choir where she saw everyone and everyone saw her. On occasion she was asked to use a baton and to help lead the congregation in the singing of hymns. She helped count the offerings after they were collected by sorting change into appropriate piles. On some unique occasions Jessica was asked to give the prayer closing the service.

Jessica’s worship experience changed completely as a result of these strategies. She became an active participant in church services and got more out of them personally. In turn, the church family learned about the need to devise worship strategies that actively included and involved Jessica, and their worship experience was enhanced by Jessica’s active involvement. Many church members now instinctively reach for Silly Putty, cartoon scriptures and other aids when they see children squirming uncomfortably during services. It changed the way they thought about kids’ challenges. They realize now that it is a person who is **having** a problem rather than a person who **is** a problem. Jessica’s vocal outbursts became a distant memory, and she and her family now receive increased enjoyment of their worship activities.

## Real Life Choices is Launched

*Continued from the cover*

**"Participating in Real Life Choice represents a 'win-win' situation for families and individuals..."**

waiting list do so only because the state offers no other services for those who would rather keep the disabled family member with them at home. Now, there is another option.

Building on five years of experience with Self-Determination, the Division is embracing person-centered planning and self-directed services through Real Life Choices.

"This is not a deficit model of planning," says Palsho. "Like Self-Determination, the planning process in Real Life Choices takes into account the strengths and capacities of the family and the individual. Instead of asking 'what *can't* this person do?,' we are asking 'what does this person like to do and do well?' We build from there and design services and a budget around the needs."

In order to help ensure equity in budgeting, the planning process includes determining a level of need. Using an Individual Support Tool, families and division staff gauge the amount of services a person needs and how much DDD funding will be allocated. There is a direct link between the individual's capacity for self-care and the amount and intensity of support time needed. The resource tool statistically assesses individual and places them in one of four dis-

tinct levels of need which correlates with individual budgets.

According to the Division, it seems to be working.

"In our early sessions with families, we have found that very few felt the level of funding assigned was inadequate," said Palsho. "In fact, most families were very pleased...some even felt it was too much."

Real Life Choices reflects a win-win opportunity for families and individuals.

"People are used to losing something if they accept something," said Kathy, "but this is different. Families can participate in Real Life Choices and still keep open the option of a supported living situation outside the family home in the future. You don't give up anything; if you need more services at a later time, you will get more services."

Real Life Choices also reflects a win-win for state government. Real Life Choices should cost the state less money than relying primarily on providing group homes, which cost roughly \$90,000 per person a year. It also will provide more federal matching funds -- fifty cents for every dollar spent -- under the Community Care Waiver, a Medicaid program.



## **A Family Handbook on Future Planning**

A Family Handbook on Future Planning is a guide to help families develop a future plan for their sons or daughters with cognitive, intellectual or developmental disabilities that provides personal, financial and legal protections for these individuals after the parents either die or can no longer provide care or support.

The handbook is designed to help families review and inventory the needs and strengths of their family member, determine what should be in a plan and then locate qualified professionals and resources to finalize the plan. It is an update of an earlier publication on Future Planning published by The Arc in 1991 and incorporates new information. This guide is intended for publication on the World Wide Web, as most of the resources it cites are found on the Web.

It can be found at [www.thearc.org/futureplanning](http://www.thearc.org/futureplanning)

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## new directions

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## SATURDAY, April 17, 2003

### 3rd Annual Statewide Gathering on Self-Directed Supports

*keynote presenter: Jackie Golden*

### **April 17, Doubletree Hotel - Somerset**

Jackie is a national parent leader, whose son Joshua is in a self-directed supports process. She will tell their story, what they are doing, and also, in two workshops, talk about how they have developed a microboard model called a self directed support corporation (kind of like an incorporated circle of support) around their son Josh.

Learn more about housing options, creative budgeting, Circles of Support, developing good plans, finding and supporting good staff, getting involved in your community, and finding good jobs. Join other families and people with disabilities who are directing their own services and supports. Learn from each other and the experts.

**for more information, contact Joan Smith at the Boggs Center  
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